

## IV. SYSTEMS DEVELOPMENT

**T**he National Family Caregiver Support Program (NFCSP) should serve as a catalyst for the aging network to construct a multifaceted and coordinated system of supports and services to respond to the needs of caregivers. In general, “system” refers to structures and organization around which customers and services come together. Creating strong infrastructure becomes critical to establishing and sustaining such a system, yet the infrastructure must also be flexible enough to support appropriate and integrated services.

Caregivers currently face a highly fragmented “system” of services that operates within and outside what is traditionally considered the aging network. This system relies on diverse public and private funding mechanisms as well as uncompensated supports provided by volunteers. The advent of the NFCSP offers the network a unique opportunity to leverage and transform this uncoordinated assortment of services and funding mechanisms into a true system that meets the diverse needs of caregivers.

This systems change opportunity also brings a fundamental challenge for the aging network—to transition from an emphasis on service delivery to longer-term capacity building efforts for creating an integrated system to support caregivers. To maximize the NFCSP effect, most resources should be used to leverage existing programs and expertise rather than delivering services to individuals. Generating a critical mass of stakeholders to establish and sustain a system of services and supports for caregivers is in the interest of the aging network. Because of limited funding, the ability to effectively reach and serve the caregiver population becomes inextricably tied to partnerships with other agencies and organizations to leverage and coordinate resources for creating positive outcomes at the state, local, and caregiver levels.

This chapter addresses some of the key issues that should be considered in developing strategies for systems change to implement a responsive caregiver service and support system. Topics covered include:

- Guiding principles for systems development;
- Strategies, including integration with other programs and service systems, partnerships, financing, and visibility; and
- Practical information for planning and assessment to develop viable strategies.

### **GUIDING PRINCIPLES FOR SYSTEMS DEVELOPMENT**

Whether designing a new or expanding an existing caregiver support program, developing goals to guide the effort is important. As Lynn Feinberg suggests, goals for a caregiver support program should promote: 1) seamless support services, 2) efficient use

of resources, and 3) positive outcomes for caregivers.<sup>1</sup> The meaning of these goals might vary, depending on the perspective of each particular stakeholder. Therefore, in developing program goals, involving a full-range of stakeholders, including caregivers, in the process is beneficial.

The following eight guiding principles, developed by Feinberg, represent key considerations for developing an effective and responsive caregiver support system:<sup>2</sup>

- **Family Role.** Family and informal caregivers are legitimate clients within the organizational field of long-term care.
- **Access.** Services should be available throughout the caregiving process, and caregivers of all ages and income levels should have access to good quality information and support services wherever they reside.
- **Coordination.** Caregiver support systems must coordinate services and leverage existing infrastructures and resources, rather than reproduce the patchwork of services that vary from state to state and community to community.
- **Comprehensive Services Offering Choice.** Caregiver support services should offer a seamless array of services that address a range of caregiver needs and be flexible enough to meet these needs as they change over time.
- **Diversity.** Systems must strive to meet the increasingly culturally diverse and changing population of caregivers, such as working caregivers.
- **Participation.** Families and care recipients must be involved in service planning and delivery as well as care decisions.
- **Respect.** Systems must respect the needs of the caregiver while preserving the dignity and autonomy of the care recipient.
- **Accountability.** Systems for assuring good quality care and outcomes must be integrated into all caregiver support programs.

## SYSTEMS DEVELOPMENT STRATEGIES

The NFCSP strives to stimulate the development of a responsive caregiver support system at the state and local levels. The ideal system will offer caregivers a continuum of services that will meet their needs at all phases of their caregiving careers—helping them identify as caregivers, reaching out and supporting their needs, and providing information and services such as respite when necessary. This system will promote seamless services, use resources efficiently, and achieve positive outcomes for caregivers by reaching them at the “servable moment.”<sup>3</sup> To develop and sustain this system

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<sup>1</sup> Feinberg, L.F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

<sup>2</sup> Feinberg, L.F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

<sup>3</sup> Montgomery, R.J.V. (2001). *Change, Continuity and Diversity among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

capacity, a subtle, yet important, shift must occur in the imaginations of aging network planners. A responsive system for caregivers is less about individual assistance through services and more about information brokerage and enhancing service capacity to ensure that the system can reach a broader population base. To develop or expand existing programs into a seamless and responsive system, a number of strategies can be employed.

### **Integration with Other Programs and Service Systems**

As the aging network establishes priorities and plans for the NFCSP over time, a key consideration will be the desired level of coordination between caregiver programs and the broader long-term care system. Establishing the caregiver program separately can preserve the program's primary focus on caregivers, avoid restrictions on flexibility imposed by other programs, simplify the long-term program planning process, and maintain clearer reporting. Integration permits the aging network to leverage resources with other efforts, directly address the problem of system fragmentation, and approach the needs of the "family" unit more holistically. Medicaid, particularly 1915(c) waivers, provides an opportunity to capitalize on existing services for care recipients to provide support for caregivers.<sup>4</sup> Several factors influence decisions to integrate or segment the caregiver support system from the broader system, including the existing system's configuration, the current role of State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) within the system, the presence of funding for caregiver support programs from non-Older Americans Act (OAA) sources, advocacy groups representing caregivers, and the political and economic environment at the state and local levels.

Currently, states use different approaches to develop and expand the capacity of caregiver systems. For example, Maine operates through some AAAs a state-sponsored respite program for caregivers of people with Alzheimer's Disease. The program functions apart from the long-term care system at the state and local levels. To implement the NFCSP, the state is using a similar approach and will keep the program separate from the long-term care system. Moreover, to ensure that the new program meets the state's goal of reaching a broader population than Alzheimer's caregivers, the state is requiring AAAs to demonstrate that they are serving new populations in their plans and reports. Maine determined that segmenting the NFCSP effort from other long-term care programs, such as those covered by Medicaid, would preserve local flexibility and eliminate administrative issues such as incompatible service definitions and rigid reporting requirements.

Pennsylvania's approach is an example of a program that started as a separate initiative and evolved into a more integrated system of caregiver support. The program began as a state-funded pilot effort with dedicated staff and, in many AAAs, as an initiative segmented from other ongoing programmatic activities. Over time, the Department of Aging encouraged greater integration of the program into the broader system by integrating service components funded through the Medicaid Home and Community-

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<sup>4</sup> Smith, G., Doty, P., and O'Keefe, J. (2000). *Supporting Informal Caregiving (under Medicaid)*. Available at <http://www.aoa.gov/carenetwork/Fin-Smith.html>.

Based Waiver (HCBW) program, quality monitoring reviews, computerized systems for assessment and reporting, and regular communication among the AAAs. The program is based on an integrated care management model. NFCSP activities will operate with a similar goal of service integration.

From the start, Minnesota and North Carolina used an integrated approach to plan and implement the NFCSP. For Minnesota, the timing of the NFCSP coincided with a broad, legislatively mandated long-term care system reform, which includes such efforts as expanding existing information, assessment, and consultation services; funding the development of new community-based services; and enhancing quality and improving consumer satisfaction. The lead state agency, the Department of Human Services, views the NFCSP as an opportunity to augment this broader state effort and is seeking ways to integrate the program into the broader system. The existing centralized information and assistance function—Senior LinkAge Line®—offers a visible place to begin this integration. The Senior LinkAge Line® is a 1-800 number that provides information and assistance, if needed, to the elderly and their families regarding programs and services available across the health and social service sectors. Under the NFCSP, this service will be enhanced to offer more consultation to a broader population of caregivers. Minnesota is also exploring ways to integrate NFCSP reporting into a broader effort to develop a streamlined data reporting system that integrates data from all programs associated with the long-term care system. Given the variability of reporting requirements and service definitions associated with the different funding streams involved, this effort represents no small task.

Despite the administrative and planning challenges, both Minnesota and North Carolina decided that coordination and integration offered worthwhile benefits, such as reduced startup costs and other efficiencies associated with aligning their programs with other components of the system. Given the limited resources and large demand for caregiver support programs, any opportunity to leverage resources should be carefully considered. Whether SUAs and AAAs choose to pursue separate programs or work to integrate caregiver supports into the broader system, the aging network is encouraged to examine the advantages and disadvantages of these strategies, seek the appropriate blend of these strategies as the NFCSP evolves over time, and identify barriers to integration and collaboration, or both.

## **Partnerships and Collaborations**

In both integrated and independent caregiver support systems, partnerships, and collaborations with state and local agencies, providers and other stakeholders serve as cornerstones for effective and responsive program development. The aging network has long used partnerships to build programs. SUAs and AAAs commonly partner with each other and providers to carry out OAA Title III programs. In the past, they also have partnered with non-aging network entities to improve service delivery for special segments of the over-60 populations, such as older persons with disabilities. The 1987, 1992, and 2000 OAA amendments, for example, encourage SUAs and AAAs to work with state and local disabilities agencies to plan and develop services for older disabled persons and allow younger disabled adults to be served at congregate meal sites when they accompany their eligible parent or caregiver. Developing a strong network of

partners offers the aging network the opportunity to build a more coordinated and effective system while maximizing resources to increase access to caregiver programs.

A diverse group demographically, caregivers demonstrate a variety needs. One of the fundamental challenges inherent in building a responsive caregiver system is developing a system with more than a crisis-response capacity. This difficulty entails building capacity for early identification and programmatic elements sufficient to deliver the right service at the right time.<sup>5</sup> To build this capacity, the aging network must become creative and consider forming alliances with traditional and non-traditional sectors and organizations. In the broadest sense, the NFCSP spans at least four major sectors within states and communities: the political system, health and human services system, employers, and the faith community. That these sectors recognize their respective roles and responsibilities for caregivers is essential. The list of potential partners and collaborators will vary by state, but could include such entities as:

- State Government – governors, legislators, legislative committees, senior legislatures, and state agencies (e.g., mental health, developmental disabilities, facility services, medical assistance, Medicaid, vocational rehabilitation, housing, agriculture, etc.)
- Advocacy Groups – caregiver alliances, AARP state and local chapters, Alzheimer’s state and local chapters, long-term care advocacy groups, disability groups, councils on developmental disabilities, state associations on aging, and ARC (formerly the Association for Retarded Citizens)
- Providers and Their Representative Groups (both long-term care-oriented and broader health) – state assisted-living associations; state health care facilities associations; respite providers; hospice and end-of-life care organizations; home care associations and organizations; physician, nursing, social work, allied health provider, geriatric medicine, and gerontology associations (*Exhibit IV.1*)
- Employers – chambers of commerce and other business associations, employers with interest, large employers that offer caregiver programs, minority business coalitions
- Faith-Based Associations and Organizations – social service organizations, caregiver and home care agencies (*Exhibit IV.2*)
- Others – legal services, state cooperative extension services, state alliances of information and referral services (AIRS), universities, research institutes, community colleges, and area health education (AHECs) (*Exhibit IV.3*)

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<sup>5</sup> Montgomery, R.J.V. and Kolsloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at <http://www.aoa.gov/carenetwork/issuebriefs.html>.

### Exhibit IV.1 AAA Partnership with Primary Care Providers

**Title:** Primary Care Physicians Partnership

**Affiliation:** Eastern, Aroostook, and Senior Spectrum AAAs (Maine)

**Status:** Developmental

**Approach:** These three AAAs are working collaboratively with medical providers on supporting family caregivers. They hired staff from the University of Maine to set up educational and measurement tools. The project involves screening all adults (age 18 and over) who visit a participating primary care practice for routine health care. Patients are asked to complete a brief screen, identifying caregiver stress, as they wait to see the physician. If the screen identifies stress, AAA project staff will contact the caregiver to offer assistance. The program encourages physicians, physician's assistants, and nurses to take a more proactive and holistic approach. It is hoped that these steps will allow the AAAs to reach caregivers earlier in their caregiving career and, thus, decrease their burden.

**Cost/Funding:** Three-year AoA grant funded.

**Contact Information:** Roberta Downey, Executive Director, Eastern AAA, at [redowney@eaaa.org](mailto:redowney@eaaa.org) or (207) 941-2865, ext. 121.

### Exhibit IV.2 AAA Partnerships with the Faith Community

**Title:** Development of Community Partnerships

**Affiliation:** Pierce County Aging and Long Term Care (Washington AAA), Respite and Crisis Care Coalition of Washington

**Status:** Operational

**Approach:** Pierce County is working with the Respite and Crisis Care Coalition of Washington (RCCCW), a consortium of agencies that provide respite for caregivers, to track caregiver needs and available resources that may not be utilized or are underutilized. The goal of this effort is to expand options for service provision by enlisting the assistance of programs such as Interfaith Care Team Ministry, which relies on members of faith communities to assist older adults in a variety of ways, and Senior Companion, which recruits seniors to provide practical help to those in need.

**Contact Information:** David Hanson, Program Specialist, Pierce County Aging and Long Term Care, at [dhanson@co.pierce.wa.us](mailto:dhanson@co.pierce.wa.us) or (253) 798-3807.

### Exhibit IV.3

#### SUA Partnership with a University to Facilitate Capacity Building and Exchange among Geographically Separated AAAs

**Title:** Staff Videoconferences

**Affiliation:** North Carolina Division of Aging (SUA)

**Status:** Operational

**Approach:** The SUA collaborates with UNC Cares to facilitate bimonthly videoconferences between the SUA and the AAAs. Seven to eight sites across the state have between 3 and 10 participants. Lasting two and one-half hours, the videoconferences are productive, with one-third dedicated to information sharing, one-third offering a training opportunity, and the last third devoted to technical assistance. Participants feel most comfortable participating if at least three people are at each site. The videoconferences allow staff to save travel and time.

**Cost/Funding:** Because UNC Cares operates the videoconferences through the university system, no cost is associated with them. Some community colleges also offer free sites. However, if they ran the videoconferences through the state system, each conference would cost a few thousand dollars.

**Contact Information:** Dennis Streets, Planning, Budget and System Supports Section Chief, North Carolina Division of Aging, at [dennis.streets@ncmail.net](mailto:dennis.streets@ncmail.net) or (919) 733-8400.

For more detail on building partnerships and collaborations around issues related to caregivers of people with developmental disabilities and grandparents as caregivers, refer to the Janicki and Minkler issue briefs at <http://www.aoa.gov/carenetwork/IssueBriefs>.

The following sections discuss three forms of partnership, i.e. 1) networking, 2) formal partnerships, and 3) financing, and strategies currently being used by the network to carry them out.

### Networking

SUAs, AAAs, and ITOs can begin to develop caregiver programs through informal networking within and outside the aging network. Networking permits the identification of individuals and organizations with interests in caregiver issues. Informal networking helps to: 1) identify and build a critical mass of interest around caregiving; 2) build constituencies for support, advocacy, and visibility; 3) spawn creative strategies and approaches; and 4) identify core programmatic goals for short- and longer-term strategic planning and action. Informal networks can become more formalized through conferences and regular meetings.

In the planning phase of caregiver system development, networking offers an invaluable means by which SUAs, AAAs, and ITOs can identify and prioritize issues as well as learn about and leverage existing programs, resources, and services to create a responsive caregiver program. An effective way to create and extend networks around caregiver interests and issues is to establish task forces and advisory councils, at both the state and local levels. Numerous state and local governments already sponsor task forces to address issues concerning aging and long-term care. These groups can serve as

natural launch points for developing task forces or committees on caregiver issues. However, to increase visibility and enhance opportunities for buy-in across a broader base of stakeholders, establishing task forces and advisory groups separate from groups with a core focus on aging interests might prove advantageous. These established groups and constituencies can be invited to sit on the caregiver task force, but opening the forum to a broader range of stakeholders is vital, including providers, social service agencies, mental health programs, Alzheimer's chapters, adult day services programs, the business community, universities, caregiver advocates, and consumers. **Exhibit IV.4** highlights one AAA's efforts to establish an advisory task force that networks across several sectors.

#### **Exhibit IV.4** **AAA-Established Advisory Task Force**

**Title:** Inland and Coastal Advisory Councils

**Affiliation:** Senior Spectrum (Maine AAA)

**Status:** Operational

**Approach:** Staff at the AAA contacted a diverse group of community members with interests in supporting caregivers to serve as members of two advisory councils that will consult with the AAA about NFCSP issues and plans. Staff either emailed or called individuals at known organizations, stating the purpose of the council and ensuring that all meetings would be efficient and task oriented, which led to successful recruitment. Members range from elder law attorneys, to caregivers, to grocery store workers and members of the chambers of commerce. Enthusiastic council members considered the first meetings of the advisory councils and the AAA, which took place in September 2001, successful and wanted to meet bimonthly instead of quarterly.

**Contact Information:** Debra Halm, Senior Director, Senior Spectrum, at [dhalm@seniorspectrum.com](mailto:dhalm@seniorspectrum.com) or (800) 639-1553, ext. 119; Leslie Shaffer, Senior Spectrum, at [lschaffer@seniorspectrum.com](mailto:lschaffer@seniorspectrum.com) or (800) 639-1553, ext. 106.

### **Building Partnerships**

Compared to networks, partnerships and collaborations among agencies and providers tend to be more formalized and occur after program goals, desired outcomes, and specific approaches for achieving these outcomes have been identified. Opportunities to establish partnerships and collaborations exist at and between the state and local levels and across the public and private sectors (**Exhibit IV.5**). As with other OAA programs, SUAs, AAAs, and ITOs typically create relationships by defining a particular service that will be offered using NFCSP funding and then issuing a request for proposals (RFPs) to solicit vendors and providers. **Exhibit IV.6** describes a new approach undertaken by Senior Spectrum, a Maine AAA, when it issued a request for collaboration to seek *partners* for implementing the program, as opposed to *contractors* to provide services.

### Exhibit IV.5

#### State-Initiated, Cross-Agency Collaborations to Create a Multifaceted and Responsive Caregiver Support System

**Title:** Cross Agency Collaboration

**Affiliation:** North Carolina Division of Aging (SUA)

**Status:** Operational

**Approach:** The SUA is collaborating with a number of organizations to serve caregivers. Partnerships have been formed with the following organizations: Cooperative Extension, which trains staff regarding eldercare and grandparents raising grandchildren; Hospice and End of Life Care, which provides training to health care professionals, faith-based leaders, and the public on end-of-life planning, and is working on the upcoming PBS caregiver series; Duke Long Term Care Support Center, which is acting as a consultant to the SUA and AAAs in NFCSP training; UNC Cares, which is facilitating the videoconferencing and assisting in data collection planning and evaluation; and AARP, which is getting the word out to caregivers and has worked with the SUA in the Grandparents Raising Grandchildren National Teleconference. In addition, the Division on Aging (DoA) is encouraging AAAs to partner with other agencies serving caregivers and to leverage funds. The DoA provided a list of required agencies for AAAs to speak with regarding collaborative efforts.

**Contact Information:** Dennis Streets, Planning, Budget and System Supports Section Chief, North Carolina Division of Aging, at [dennis.streets@ncmail.net](mailto:dennis.streets@ncmail.net) or (919) 733-8400.

### Exhibit IV.6

#### AAA-Initiated Partnerships with Community Organizations to Identify and Provide Services and Supports to Caregivers

**Title:** Developing Community Partnerships

**Affiliation:** Senior Spectrum (Maine AAA)

**Status:** Operational

**Approach:** Senior Spectrum created a seed-money fund to support collaborations with community organizations or businesses for effectively identifying and providing resources to caregivers in their community. The AAA targeted specific organizations, including home health agencies and boarding homes, and placed a notice in the daily news asking interested parties to respond to a request for collaborations (RFC). The AAA selected four of eight applicants based their plans to meet documented guidelines; reach caregivers; staff tasks; meet reporting requirements, which include a one-page progress report halfway through the year-long grant and a two-page final report; build capacity; and sustain the collaborative relationship beyond the seed money.

**Cost/Funding:** A total of \$5,000 was set-aside for the seed money. The AAA was willing to award grants of \$500 to \$2,500. Three organizations were fully funded and a fourth was partially funded.

**Contact Information:** Debra Halm, Senior Director, Senior Spectrum, at [dhalm@seniorspectrum.com](mailto:dhalm@seniorspectrum.com) or (800) 639-1553, ext. 119; Leslie Shaffer, Senior Spectrum, at [lshaffer@seniorspectrum.com](mailto:lshaffer@seniorspectrum.com) or (800) 639-1533, ext. 106.

## Financing

Before the NFCSP, many states, AAAs, and tribes identified the need for caregiver supports for their communities and developed programs accordingly using a variety of federal, state, local, and private funding sources. A less common, but possible, funding approach is the use of cost sharing or sliding scale fees to fund programs.

During the planning and implementation phases of the NFCSP, states, AAAs, and tribes should examine the full array of financing options, including opportunities to blend and leverage funding streams. As noted in the introduction of this chapter, system and service fragmentation, a common attribute of caregiver programs, partially stems from the diversity of funding sources. These disparate funding streams have led to incremental and uncoordinated development of programs and services and have threatened the realization of an effective caregiver support system. Because of the fragmentation within the reimbursement environment for caregiver support programs, estimating the relative contribution each funding source represents for a caregiver support system is difficult. In Pennsylvania, an estimated 50 percent of the funding comes from local sources, 13 percent from federal sources, and 37 percent from state general funds and the Medicaid HCBW (including the state match).

The diversity of funding streams creates some inconsistencies in eligibility and service implementation across and within states and localities. Moreover, within states, a great deal of variability in financing and resource availability among AAA planning and service areas can exist. Further complicating the resource and planning picture for AAAs is the existence of other community-based funders and providers, such as United Way chapters, local foundations, and local community group fundraising, which create additional streams of resources that support large and small caregiver support efforts. These efforts often are outside the purview and control of the AAA or ITO. That AAAs and ITOs seek and identify strategies is important to coordinate with and encourage other existing community-based caregiver support efforts. This procedure will enable AAAs and ITOs to ensure that their activities avoid duplicating or competing with other programs in their communities, and, in the long run, facilitate the creation of a more robust and multifaceted system to support the diversity of caregivers.

In addition to the traditional funding sources, the aging network should examine and consider the viability of policy reforms and other options that will generate additional resources for the caregiver support system. For example, the state of North Carolina identified sources such as corporate tax incentives to create subsidies for eldercare, tax relief for long-term caregiving and expenditures, state expansion of medical leave policies, integration of work and family issues with planning for economic development, and consumer-directed care. Pennsylvania uses a cost-sharing strategy for reimbursing caregiver services. Services like counseling and training are provided free, regardless of income. For services such as respite and durable medical equipment, reimbursement is based on a sliding fee scale. If income is less than 200 percent of the federal poverty line, services are free. Between 200 percent and 380 percent of the poverty line sliding fee scale applies, with clients required to pay 10 percent of services for every 20 percent

income increment. If income is greater than 380 percent of the poverty line, clients must pay the full cost of the service or product.

### **Visibility and Advocacy**

Once programs and services are ready to operate, visibility and advocacy becomes an essential component of caregiver systems development. Promoting awareness of and support for caregiver issues can occur in a variety of sectors, including state residents, health and human services agencies and providers, employers, the faith community, and state and local governments. Without expanded visibility and active advocacy, establishing a responsive and successful caregiver system will be a constant challenge.

Many SUAs, AAAs, and ITOs use social marketing strategies to increase awareness and recognition of caregiver issues and needs and to generate support for and knowledge of caregiver supports and services. These marketing strategies vary widely in their goals, scope, and cost and include such activities as developing and disseminating brochures, fact sheets, and other educational materials; producing newspaper, newsletter, and television advertisements containing information about assistance services and caregiver support groups; and conducting public awareness campaigns using billboards, print ads, and television and radio spots.

SUAs, AAAs, and ITOs realize the advantage of coordinating visibility efforts to maximize resources, minimize duplication, and ensure a uniform, consistently communicated vision for the caregiver support system. For example, the SUAs in Maine, Minnesota, and North Carolina work actively with AAAs to develop and coordinate educational and marketing efforts. In Maine, the SUA decided from the start to earmark a percentage of the NFCSP allocation for marketing and educational material development and currently works with the AAAs to develop materials that will convey a consistent message statewide. North Carolina has drafted an RFP to solicit a vendor to develop an Integrated Marketing Communications Plan for Family Caregiver Support Programs in North Carolina.

Many efforts are also being initiated at the local level. For example, the South Central Kansas AAA received a grant award from Administration on Aging (AoA) to support a statewide Caregiver Marketing and Information Campaign, detailed in **Exhibit IV.7**.

In developing brochures and other marketing materials, several elements of successful social marketing efforts should be considered:

- **Targeting Audiences and Understanding Information Needs.** To develop the most effective messages for educating and effecting changes in a particular population's understanding of or behavior around caregiving, a solid understanding of the target audience is imperative. This knowledge encompasses the social and demographic characteristics (e.g., economic status, age, education, etc.), their psychosocial characteristics (e.g., attitudes, values, motivations, behavioral patterns), and their needs. Obtaining this information, particularly data on psychosocial characteristics and needs, will require application of tools common in market research, including conducting surveys and focus groups. The objective of obtaining this information is

- to ensure that the messages and materials developed are effective for each population segment you are trying to reach. Realizing this objective will ensure that the message is compatible with the cohort, cultural, and religious morays of each group. In many cases, tailoring your messages to the specific needs of different target populations is necessary.
- **Identifying Information Distribution Channels.** Information distribution channels include television and radio as well as billboards and bus stop shelters, magazines, newspapers, posters, and other print media. Caregivers can also be reached through the care recipient. A vital consideration in the selection of information channels is what source the target groups access regularly and which sources they perceive as most credible. Social marketers note that familiarity with the medium and the performers enhances message acceptance.
  - **Evaluating Cost.** Cost is an important factor to consider when developing a visibility or marketing campaign. Television advertisements can be extremely expensive, especially during prime time. Bearing in mind the goals of the campaign and matching the chosen approach to these goals is important. For example, if the goal is to reach working caregivers, a logical communication channel might be a television advertisement or feature on the evening news. However, a lower tech, but potentially more effective and direct, approach might be developing a partnership with a local business and including a brochure on caregiver issues in employee pay checks. Similarly, a brochure advertising a 1-800 information and assistance (I&A) number could be tucked into the monthly utility bills.

### Exhibit IV.7 Public Awareness Effort

**Title:** Caregiver Marketing and Information Campaign  
**Affiliation:** South Central Kansas Area Agency on Aging  
**Status:** Developmental  
**Target Population:** Family caregivers

**Approach:** The objective of this campaign is to increase public awareness of caregiving through a statewide paid media campaign, providing caregiver tips and resources using television (e.g., half-hour shows, commercials, news segments), radio, and billboards. In addition, the campaign will advertise a 1-800 caregiver line. The NBC affiliate is committing a \$75,000 in-kind match. The outcomes of the campaign include increased earlier self-identification by caregivers and greater use of caregiver resources. Campaign products will include training videos, reports on effective marketing tools for reaching caregivers, and copies of caregiver shows that can be shared with other states.

**Cost and Funding:** AoA grant funded

**Contact Information:** Stacey Boothe, Caregiver Campaign Manager, South Central Kansas Area Agency on Aging, at [ksaaaa@hotmail.com](mailto:ksaaaa@hotmail.com) or (316) 681-2144.

**Exhibit IV.8** demonstrates each of the elements of a successful social marketing campaign and applies knowledge gained from these activities to service delivery.

### **Exhibit IV.8 Social Marketing and Service Policy Strategy**

**Title:** OAA Caregiver Programs  
**Affiliation:** Area Agency on Aging of Pasco-Pinellas AAA (Florida)  
**Status:** Operational  
**Target Population:** Family caregivers of individuals age 60 and older.  
**Approach:** The NFCSP Title III-E Program has a three-phase implementation plan that consists of: a determination of needs, caregiver forums, and service implementation in both Pasco and Pinellas Counties. The needs assessment phase, conducted largely through a contract with the University of South Florida, included a review of caregiver literature, interviews with stakeholders, focus groups, public hearings, and an evaluation plan to provide a blueprint for evaluating the effectiveness of implementing the final recommendations. During the next phase, caregiver forums were held on a variety of topics to offer support to caregivers and to gain feedback concerning their needs. Service implementation will be based on recommendations gleaned from the first two phases to ensure that money and energy are applied to development of services that caregivers want and need.  
**Cost/Funding:** AoA grant funded.  
**Contact Information:** Beverly Burton at [burtonb@elderaffairs.org](mailto:burtonb@elderaffairs.org) or (727) 570-9696 ext. 253; Sally Gronda, Executive Director, at [Grondas@elderaffairs.org](mailto:Grondas@elderaffairs.org) or (727) 570-9696 ext. 266.

## **SYSTEMS DEVELOPMENT PLANNING AND ASSESSMENT**

A key to the aging network's success in implementing Title III programs is the balance of local-level flexibility with state-level accountability. The success of a caregiver support system requires a similar commitment to flexibility, but not just between the state and local levels. To realize the potential of the NFCSP to create systems change and expand support for caregivers, a commitment to flexibility and coordination must exist, coupled with systematic planning across all facets of the long-term care system.

### **Systems Assessment**

The structure and capacity of long-term care and caregiver systems varies by state. Some states, such as California, have legislated and financed, using state general funds, separate programs to support caregivers. Others, like Wisconsin, Minnesota, and North Carolina, have integrated caregiver support programs and funding into the community-based long-term care system. A significant first step in planning or expanding a caregiver support system at the state level is assessing the capacity of the existing long-term care system to address the needs of caregivers. Program planners must examine the existing capacity and potential building blocks of the system for:

- Type of Caregiver Served/Eligibility Criteria for Existing Services – any caregiver: low socio-economic status, grandparent, parent of the developmentally disabled, Alzheimer's Disease, etc.

- Services and Supports Offered – information and assistance, respite, support groups, supplemental services, caregiver assessments, caregiver planning, adult day services, in-home services, home-delivered meals, “best practices” related to family-centered practice and employer eldercare, etc.
- Sponsoring Agencies – aging, health and human services, developmental disabilities, mental health, education, etc.
- Reimbursement and Financing Sources – Medicare, Medicaid, OAA, state general funds, tribal funds, foundations, philanthropic organizations, and financial assistance programs such as tax credits, low-income housing, and medication assistance, etc.

**Exhibit IV.9** provides a framework for assessing the caregiver support capacity of a state or local system. This framework can be used to organize a variety of planning-related activities, including assessing NFCSP readiness; identifying the functions for the state in terms of providing technical assistance, data collection, and tool development; as well as goal setting for each component of the NFCSP.

The framework provides an approach for assessing an existing system and service environment for each of the NFCSP service components by population. Completing this exercise by population coincides with the way grants and programs are funded. This approach also offers a way to think about potential for moving the overall system and services toward universal access. Another application of this framework is to use it as a point of discussion with partners to identify caregiver activities occurring outside of the aging network.

### Exhibit IV.9 Caregiver Systems Change Capacity Assessment Framework

Repeat for each service component: 1. Information, 2. Assistance, 3. Respite, 4. Education, 5. Supplemental Services

Programs and Services							
Populations	In Network	Outside Network	Partnerships	Integration	Advocacy	Funding	Caregiver-Directed Support
<b>OAA Priority</b>							
Socio-economic Status Disadvantaged							
Developmental Disability							
Grandparents							
<b>State Priority<sup>1</sup></b>							
Alzheimer's							
Working							
Minority							
Rural							

<sup>1</sup> Example caregiver populations that SUAs and AAAs might target.

Step 1: **Environmental Scan.** Record existing programs, services, and activities by population for each of the five NFCSP service components.

Step 2: **Goal Setting.** Specify short- and long-term goals for each framework element (i.e., column headers).

Step 3: **Identify Barriers and Facilitators.** Identify barriers and facilitators for implementing, achieving, and sustaining program goals.

Step 4: **Goal Analysis and Refinement.** Analyze capacity to achieve goals and refine objectives, if needed.

## Needs Assessment

An additional approach commonly used in program planning and implementation is conducting a needs assessment (see David Hanson's issue brief at <http://www.aoa.gov/carenetwork/issue.briefs.htm>). The goal of this exercise is to determine how many people need what types of services and supports. Various methods can be used to conduct a needs assessment, including surveys, secondary data estimates (e.g., census data) (see **Exhibit III.5**), focus groups, and public hearings. However, knowing where to begin with developing a survey sampling strategy or even how to frame the questions for the survey and focus groups can prove difficult. Key issues to consider include the following:

- What is the target population (e.g., caregivers associated with current care recipients, caregivers unassociated with current care recipients)?
- What are the needs of the caregivers, especially the priority populations specified in the NFCSP legislation and those identified by the state or locality?
- Which of these needs is most immediate?
- Which stakeholders should be involved in the planning process?
- What is the timeframe for the planning process and program implementation?
- What state, tribes, and local agencies and providers (e.g., disability, social services, education, health care) currently fund or deliver services to the caregiver population?
- What resources currently are available for the target caregiver population or populations?
- What challenges that will affect the development of a caregiver support system are anticipated?

**Exhibit IV.10** discusses the efforts of the AAA in Pierce County, Washington, to conduct a needs assessment.

### Exhibit IV.10 Caregiver Needs Assessment

**Title:** Needs Assessment

**Affiliation:** Pierce County Aging and Long Term Care (Washington AAA)

**Status:** Operational

**Target Population:** Caregivers ` questionnaire distributed to more than 500 caregivers (see Appendix B for a copy of the survey instrument) and a focus group that included caregivers and professionals who work with caregivers. In preparing to conduct the needs assessment, staff consulted data from caregiver surveys, articles, and books on the subject of caregiving; attended a national conference featuring sessions on caregiving; and followed the progress of local studies that focused on the availability and accessibility of information for caregivers. The focus group included caregivers, a caregiver support group facilitator, and staff members from an Alzheimer's/dementia caregiver support program. The focus group generated a number of ideas for conducting outreach to caregivers, refining I&A services, and involving caregivers in the NFCSP planning and evaluation processes.

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